

“I’m Constantly Thinking About Bev and Her Future”: Siblings Speak About Aging

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I never pass up an opportunity to talk to parents and service providers about brothers and sisters. I can—and sometimes do—talk all day about sibs’ unique joys, concerns, and contributions and the implications they have for families and agencies. But if I have time for only one message, it is this: Brothers and sisters are too important to ignore because they will be in the lives of family members with special needs longer than *anyone*. Brothers and sisters will be there after parents are gone and special education services are a distant memory. However, if they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.

No single topic is more worrisome for siblings than the future well being of their brothers and sisters who have disabilities. Their concerns are obvious for anyone who cares to listen: their brothers and sisters with disabilities are now routinely outliving their parents; many of their parents are reluctant to plan for the future; and waitlists for Home and Community-Based Services are as commonplace as they are obscene.

In May of 2009, I invited adult siblings—ages 50 and older—to be a part of an informal online survey about the concerns they have about their siblings who are also aging and the roles they play. The results, I am sorry to report, are not optimistic. However, I hope they will serve as a wake-up call for parents, policymakers, and service providers who are concerned about older Americans with disabilities and their families.

Here are excerpts from the survey:

As you and your sibling with a disability are both over 50, are you or your sib already experiencing “aging issues”?

- Fortunately I am a very healthy 62. Only complaint is fatigue as I am still working full time and helping care for my mother and Patty in the evenings.
- I am not well, and I have learned that Downs and Alzheimer’s have been closely linked. I worry that I will not be healthy enough to handle whatever the future brings.
- I have heart disease and have had breast cancer. My brother had pneumonia last year and was hospitalized for two months. I see my brother's cognitive abilities worsening.
- Beverly has long out-lived her life expectancy; so the time we have with her has been a blessing. About 5 years ago, Beverly was showing changes in her behavior, mood and memory. I had her evaluated for Alzheimer's disease. I was shocked and saddened when we received the diagnosis. I was not aware that people with Down syndrome are more likely to get early-onset Alzheimer's than not. It was something that I was not prepared for. From that point on we were on a new road in Bev's life journey.
- My nieces are primarily in charge now, due to family dynamics and distance. Terry and I are the only ones left in our nuclear family, and we seem to be on the down hill slide of health and vitality. Terry seems to be in perilous condition most of the time.
- I no longer have the energy to contribute time to her in the way I used to.
- My parents are still taking care of my brother but they are weakening. He’s heavy and when he resists something he's difficult to handle. My parents won't admit they are no longer fit for everything.
- My brothers are slowing down and seem to be aging faster than the typical sibs in our family. Marty is having more frequent falls, Patrick is having back problems, and Michael’s mental illness is getting worse.

My guess is that you have given some thought to the days to come for you and your sibling who has a disability. When you look into the crystal ball and imagine the not-too-distant future, what do you see?

- Fear. I am also aging and am tired of watching for red flags in his life. My three children have offered to help but we all know that is not realistic. They all work and have their own families. I do not want to leave to them what was left to me.
- I see a further decline with possibility of Alzheimer's on top of Down syndrome for my brother. For me, I see a similar decline over more years due to cardiac issues, cancer and potential dementia.
- If I stay healthy, Tom will always have a home if he should decline in his ability to take care of himself. If not, others will have to step up. Who that will be, I do not know.
- I see me leading my own life without the restrictions of Mary's care. But doing so means that Mary might live in a facility where her care needs may not be met, and her life wouldn't be as full as it is now. It's sad to think of her not being active and getting the attention she does now.
- I see us going from crisis to crisis and possibly having to move all three of our brothers again.
- I think that she will be living out a longer life than people with Down syndrome used to have, and for that I am very glad indeed!
- I'm hoping to find a stable, safe, and stimulating place for him to live with others who have similar interests so we both can get on with "living our best lives."
- Knowing that Bev has Alzheimer's and seeing the changes that have occurred already, I know that the road ahead is going to be very rough.

Are there issues regarding your and your sib's future that you find yourself thinking about as you cut the lawn, take a shower, or drive to work?

- I think about the fairness to my husband after all these years of raising children to still have an adult/child living with us--and my own children. They're starting their adult lives with the possibility of having their aunt to take care of.
- I worry that I am going to die and there will be no one to look after him, and that the responsibility fall on my husband or children, who don't deserve the added responsibility (but then again, neither do I!).
- What worries me most is if my something happens to my sister and I would have to take over the care for our three brothers. I just don't know how I could take care of all of them by myself. I don't know that my marriage would survive that. Hell, I don't know if I would survive that.
- I wonder why so many people seem to think that Tom is so wonderfully independent that they never need to do anything, offer help, take him to a ball game, or even ask. Where is everybody?
- Other family members (nieces, etc.) disapprove of my sister's and my decision to place Patty in a group home. I worry that Patty will outlive us as longevity runs in the family and she is seven years younger than I am.
- I have been overwhelmed this past year and am seeing a social worker to help me deal with letting go of being the perfect sister. I do not want to be the first-responder any more.
- I would like to leave the area for the opposite coast but I am concerned about her not having an advocate. I am also concerned about the grief—hers and mine—that would ensue and her inability to deal with my absence.
- Yes, I fear his being alive when I am gone, needing all kinds of care, and his resisting because that is what he does when he is scared or in pain.
- I am constantly thinking of Bev and her future. My first concern is making sure she is happy and that all of her needs are being met. But at the same time I know that I have long-range planning to do, which involves possible

long-term health care and eventually her death. This is so hard for me to fathom and difficult to do without much family input.

- I worry that he's not getting enough stimulating and interesting things to do outside of his part-time job. I worry that he's bothering the neighbors too much. I'm concerned that he might be depressed, although he insists he's a 'happy person' by nature.
- I wish we could count on our needs being met by appropriate funding and how nice it would be if services were there when you need them, not so difficult to find and easy to take advantage of. It's sad to have to worry about money when it comes to her care.

Are there "hopeful signs" as you think about your sibling's future? If so, what are they?

- The most hopeful sign I have is my sister's behavior: as years go by living with me, she's more comfortable and more secure. She shows that with more smiles and attempting to use her voice more often. I hope that her life is happier as she ages and forgets the hard times in her past when she was in a bad group home.
- He loves people and seems to adapt to new activities quite well. When things change in the future, as life goes on, I think he'll manage to adapt and latch on to whatever is new for him.
- "Hopeful signs" are his financial cushion that was afforded by my mother's thoughtful planning that allowed his trust to be funded at the time of her death.
- Knowing my nieces will take care of her.
- The hopeful sign is that my other sibs and I work well as a team in a time of crisis or need.
- My sister is in a terrific group home right now; she can get around by herself on public transportation, she has wonderful, caring friends and housemates, and the staff is great with her. I can't imagine a better living situation, and it gives me hope that, if we need to find another place for her

down the line, there are other good places out there.

- Tom has been a trailblazer his whole life: he was among the first with Down syndrome to receive early intervention, go to a public school, be employed in the community and live independently. Will we be first with Alzheimer's, too, teaching the community about the needs of those who are aging?? It makes me tired to think about it.
- Not really. He will only need more help as he continues to have more health issues.

Can you tell me about your parents' efforts to plan for your siblings' future? What did they do that was helpful?

- My mother met with a lawyer who specialized in special needs trust and established a trust fund for Johnny. When we were younger, my parents always allowed us to be our own person without the expectation that we would someday care for Johnny. As a result, I never felt pressured and as a natural result of my love for him, I "care" for him in a way that promotes his independence.
- My parents raised my brother in an inclusive environment before it was the appropriate thing to do. As a result, we are all advocates for persons with disabilities and will do whatever necessary for our brother to be happy and have his needs met.
- My mother found the group home and made all the arrangements for Mary to move there. We are eternally grateful that she coordinated this move instead of keeping Mary with her. My mother died suddenly just a few years ago and it would have been much more difficult for all of us as well if we had had to find a new home for Mary at that time.
- They took care of guardianship and discussed their request to have me be the sibling who would be standby.
- Both of our parents seem to value my contribution and desire to be their strong second wind. They also value and honor my other two brothers' decisions to be less involved. It was our choice. Also, they share information.

To be sure, parents play the hand of cards they're dealt the best way they know how. And hindsight is 20/20. Given this, are there things you wish your parents had done differently?

- I wish they had kept records of my sister's health and education. Also I wish they had put into place a trust with a financial plan rather than a badly written will full of unsure directions.
- Done differently? Just about everything.
- My mother refused to make any plans until the day she died at age 86 when my brother was 48 and I was 53.
- Explore the possibility of Bev living in the community. Bev was open to the idea, but my parents held her back. They worried that she was too vulnerable and no one could care for her the way that they did.
- I wish she had included us in the planning and signed my brothers up for the waiting list.
- I wish they had forced my brother to live in an alternative setting. My mother's excuse was always, "He won't even talk about it."
- Prior to his moving it also would have been helpful if there were more expectations placed on his being responsible for helping with chores, cleaning up after himself, and not expecting the world to bend to his preferences and schedule. He also would have benefited from being expected to use social phrases to excuse himself, say please and thank you, etc. He was capable, but we acted as though he wasn't.
- They still pull rank when they disagree with me on something. I don't think they realize they are doing it, but discussions seem to come to a quick close. Also, Mom recently signed a bunch of legal papers that were poorly done... and it has been a lot of work for me to unwind all that. I wish they had made plans themselves. Neither my older sister nor I have children and this has been especially difficult for us because we are unaccustomed to being in a "parental role."
- They did virtually nothing! My dad did absolutely nothing (he left home with my brother was 12), and my mom was too ill and worn out to plan

anything for him at all. She assumed I would take over as his parent. When I die (presumably before Loren as I'm 10 years older) my son will assume responsibility.

- My mother did not include us in planning and had the wrong kind of trust. She really did not do anything that turned out to be helpful to us when we had to take over after her death.
- I wish they had encouraged her to be more independent. One of my biggest concerns for her is that she remains innocent and trusting of others and is not able to make any decisions on her own.
- My parents, unfortunately, MADE NO PLANS for Patty's future. Instead, this has fallen on my sisters and myself. Obviously we have our resentments!
- I wish they had been able to talk about their fears, or ideas. It was a different generation, of course, and they didn't want to trouble us. But it would have been quite the opposite.

Many service providers who work with adults with disabilities will be reading this article. What should they know about your thoughts regarding life with an aging sibling who has a disability?

- My brother lived at home until he was 40. I had to initiate his move after my father died and my mother was diagnosed with cancer. There really was no need for him to be with them for so long. He drove and had a job. He moved four floors down in the condo my mother lived in. She died a few months later. It wasn't my job to do this.
- My relationship with Tom is birth to death. He tells me everything. He never lies. And I am never, ever going to rest until you are doing your job properly and he is safe, healthy, and not lonely.
- I would like them to know that most siblings will have to take over the parent's job—but they won't have the authority of a parent in the disabled sibling's eyes as well as the eyes of many providers. This is both frustrating and scary.

- Many of us live in fear: Fear of doing "right" for our siblings and by our parents who expect that we will follow their example and wishes despite our inability to do so. Fear about how further involvement with one's sibling will constrict one's own life and that of one's family. Fear of wondering whether our siblings will recover from the loss of a caring parent--and who will take over if we no longer can. For some siblings, the whole service system is daunting and they worry that they won't be able to navigate it to assure that their siblings get the services they need.
- They should know that we need as much support as parents. We need info and resources. We are usually coming into this without the years of experience about the system. Many sibs are taking on the responsibilities of supporting our sibs at the same time we are helping our aging parents and raising our own kids.
- My sib is aging, AND SO AM I! Here's my message: keep my sister's programs and services running well. It would be a huge lift at a time when we have a lot of worries. Chasing services and following up on problems is exhausting, and our situations are hard to understand for people who don't have a disabled sib.
- I wouldn't know where to start. I've always been Loren's second mom as since I'm ten years older than he is. Our mother had serious mental and health issues so I tried to parent him and provide perspective and stability for him. I guess what service providers should know, or remember, is that many people with disabilities disabled come from widely divergent situations and there are many complex backgrounds interwoven into the mix. The person is not just definable by their disability; they are also defined by the environment they were lucky--or unlucky--enough to land into in the first place.
- In general, service providers should understand some sibling-guardians will be as involved as parents in caring for their siblings--but some may not because of commitments to their own families or professional lives. This isn't necessarily a bad thing for the siblings who have the disability because many times typical siblings will give them more responsibility and autonomy than parents will.
- It is often painful & disheartening because I see my sibling becoming weaker and more vulnerable. I am afraid for her for so many reasons.

- It's very stressful because I am aging too. I don't want to be in this mother role at the age of 69.
- Service providers should understand that having a sib with a disability is a life-altering event. They should know that although many of us are preoccupied with that consequence, we are still people who want to achieve, prosper and try to be happy. Even though we are not parents, we tend to be very responsible. But we need help from agencies who can provide high quality, trustworthy, uninterrupted services for our brothers and sisters.

Brothers and sisters will be in the lives of family members who have disabilities longer than anyone. There is a relationship easily in excess of 65 years. They will likely be the primary advocates for siblings who have disabilities when their parents are no longer around. And as these responses eloquently attest, these brothers and sisters desperately need parents and service providers who understand their unique concerns – as well as information and support to help their sibs have dignified lives living and working in the community.

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